



**Testimony for the Appropriations Committee  
From Medicaid PCA Live-in Clients of Griswold Home Care  
Regarding the effect on families to changes in  
new calculations for live-in home care  
Photos of Client Betty Johnson  
October 22 2014**

Griswold Home Care Client:

**Carolyn Hull**- 133 West Main Street #C-1, Cedar Grove South, **Clinton**, CT 06413 (860-669-9829)

Primary Contact: **Peggie Sypher**- 40 Spring St **Deep River**, CT 06417 (860-395-7243)

Caregiver: **Meimuna Ankrah**

Referred by: AASCC as a live in

Service began: 4/5/13

Age: 81

Client's condition: Alert, friendly, outgoing. Loves to go out with her caregiver. Plays Bingo weekly with friends, client crochets to keeps busy.

**The following text is from an interview between client Carolyn Hull and Lesley Mills, October 21, 2014**

**Hello**

**My name is Carolyn Hull. I'm 81 and still have some of my marbles.**

**If I could tell you one thing today, it would be to listen to the patient**

I've been in nursing homes several times, most recently after a car accident for 4 months when I had a hip and knee replacement.

I'd worry about not going home healthy but **they finally sent me home when Medicare ran out.**

**Otherwise I might still be there!**

People were so sick.

I'd lie in at night and things would go through my mind. Recently a lot of friends have died. I'd think, "Why not me?" Even though I'm not ready to go.

I'd get roommates who were really sick. I'd think, "I hope I don't get like" that but **it wears you down being around sick people all the time. It's sad and depressing to see lonely people and I'd think about dying a lot.**

But never thought I'd have to stay there. My sister died at 68; mother died at 86. I have a goal: to live to be 87!

**There was so much waiting in the nursing home.** I was lucky. I'm outgoing so I got more attention than I deserved but even so I'd drop and spoon at lunch. And wait. Or wait my turn to go to the bathroom.. in an hour. **Sometimes we just couldn't wait. Some people had to wear diapers just because it was easier for the staff. It's not like that at home with Meimuna. Anything I need, she's right there for me.**

And I don't lie around all day. – laying around made me weaker. Now we go out or I play solitaire on the computer.

I thought most about my cat, Greyson. I had another cat but he left. I like to think he went away to die.

Now I was a bad-ass mother. I was married 16 years had 5 children. Then I was a single mother and worked the 4-midnight shift for dispatch at the Clinton Police Department for 22 years. I would send them by my house at 8:30 every night and they'd tell me how good my kids were because it would be all dark. Actually, they would board up all the windows!

Like my mother told me when she caught me smoking a cigarette – don't let me see you do bad things. Do them inconspicuously.

This has been my home for 32 years. All my memories are here, especially family visits. It's easier now I'm not in the nursing home with rules to follow, especially for my 4 grandchildren and 8 great grandchildren. I get to see them

10.21.14

To: The Legislature of the  
State of CT

From: Wendy Gaynor  
75 N Benham Rd  
Seymour, CT 06483

Re: Estelle Lobdell  
DOB 12-30-20

I am writing to you to inform you of how important it is that my mother continue to receive her Medicaid services in her home.

Prior to receiving in-home services my mother was existing in a nursing home as a result of a fall, Oct 2013. At that time she suffered a broken hip.

While at that facility she suffered two injuries, because she fell out of her bed. On both occasions she required medical intervention, including stitches to close a head wound. This facility was rated as "5 star" according to the St Vincent's Hospital Social Worker. It was anything but "5 star." After these two incidents she

began to decline. She became confused, depressed and disoriented. She lost a significant amount of weight, she was approximately 138 lbs when she fell <sup>and broke her hip</sup> and at discharge from the Nursing home she was approximately 115 lbs. (Her lowest weight was 112 lbs) She was often found by me, "soiled." She developed bed sores on her heels and ankles. She would beg me to take her home, but that option did not appear viable. My home, which is multi-level was also not an option for her, as she was now wheel chair bound. I was so guilt ridden at the time, as each day I walked out <sup>with her</sup> I knew she was broken hearted. It didn't help that I had promised her that I would always take care of her and keep her in the home that Dad had built in 1950. The things I witnessed at the facility were so inappropriate. I can say there were good times but they were outnumbered by the bad. I can still see a worker picking a utensil up off the floor and returning it to a client to finish

eating her dinner with. I took photos of the dirt on the floor under mom's bed where staff had dropped items; as well as splatter on the wall that was not cleaned prior to mom's arrival. Her phone never worked and it took me an entire week to get it fixed; this was disturbing to family and friends who were cut-off from communicating with her.

It all turned around when I asked to meet with the Social Worker and she told me Mom might qualify for home services 24/7. My mother needed to leave that facility for her own well being and our peace of mind. When she was deemed eligible we celebrated by having a "you're going home party".

The 24/7 model of service, <sup>provided by Medicaid</sup> has made all the difference. Her bed sores are gone, she has not been unsafe or injured since returning home. She now weighs 128 lbs and lives in the home that Dad built her. That says it all. She plays cards and watches T.V. with

her care provider and is never  
left "spoiled" in her own excrement.

I ask that you continue  
to support and endorse this service  
delivery model, it has made  
a huge difference to Mom and  
our family.

Respectfully submitted,

Wendy Gaynor

cc: file

Griswold Home Care Client:

Client: **Betty Johnson**- 300 Plainville Ave #126 (860-404-0095)

PC: **Suzanne Beaulieu**- 306 East Lake Road, Ludlow, VT 05149 (802-345 8483)

Caregiver: Maame Thompson

Referred by: CCCI as a live in

Service began: 6/12/2013

Age: 86

Client's condition: Dementia, diabetic, has memory loss, may have some confusion. Walks with some assistance

### Interview by Lesley Mills October 21, 2014

In the nursing home there were too many patients and not enough aides to provide appropriate care but most of them tried hard.

When were taken for an interview at the nursing home we were shown nice rooms and relatively alert patients. We were very angry when we first went to visit Mom in her real room. The family was devastated: the quality of care was very different than what we'd seen; the rooms were appalling.

Her dementia progressed rapidly and we could see she could only feed herself 75% of the time. She dropped from 118 to 86 pounds. We looked around and saw what happened to other patients who needed to be fed. They weren't fed. It took too much time to sit with one person. If we'd left her there, she would be dead today.

I begged the Director and CCCI to help. Finally, we brought her home with live-in Medicaid care. The hard thing was to find an agency to work with us with only 1 bedroom. Before that, I'd visit from Vermont and I'd stay Tuesday through Friday. Now I come once a month so the live in caregiver can have time off.

This live-in care has been a god send! Thank you to all who made it happen. Her caregiver is so patient and attentive and Mom is peaceful.

I have no money left and neither does my mother. If Medicaid cannot pay for this with the new Federal laws, I will just have to put her back in a nursing home. And hope for availability. It breaks my heart.



October 21, 2014

Dear Members of the Appropriations Committee:

My name is Jennifer Gifford and I live at 142 Willard Avenue, Westbrook, CT. I am writing in behalf of my mother, Dorothy "Dot" Gifford, age 87, for 65 years residing at 70 Ingham Hill Road, Old Saybrook, CT.

Dot Gifford came to her home on 70 Ingham Hill Road as a young bride in the summer of 1949. In the fall of 2011 she was diagnosed with progressive vascular dementia. She continued to live by herself with daily visits from family members until the early months of 2013. At that point it became evident that she could no longer live by herself.

Dot Gifford was a shopper – not a saver. Finances limited our options and in April of 2013 I began staying overnight and the majority of each day with her. It was overwhelming to me, both emotionally and financially. My mother told me over and over that she did not want to go to a nursing home and I understood her feelings and wanted to honor her wishes. When she was diagnosed with blood clots in her lungs at the end of September 2013 and sent to the hospital I made the decision that at least for a short time she would recover at a nursing home.

Dot Gifford was a strong-willed woman. From the minute she was rolled into the nursing home she made it perfectly clear that she wanted to go home. She missed her cat desperately. He was always on her lap and cuddled up to her at night. She was very, very unhappy and strident in her desire to leave. The nursing home responded by starting her on a narcotic, and when that did not work they (against my wishes) added anti-psychotics and then an anti-depressant. None of it accomplished what they wished.

She ended up on the third floor of the nursing home. There the patients spend their days grouped in a circle in front of the nurses' station, slumped over in their wheelchairs. They are never taken outside into the sunshine or even off the floor.

During the seven months my mother was in a nursing home she had two cases of pneumonia and five UTI's. She lost 40 lbs. Because they considered her an escape risk they kept her confined in her wheelchair and she lost her ability to walk.

I had started on Title 19 but was hoping for some sort of miracle – that she would be able to return home and that somehow I would be able to afford help. And then one day it happened. I ran into a casual acquaintance who told me that her mother was home on Title 19 with full time live-in care. I made inquiries and found that my mother was a candidate for this program also.

The news gave her hope. While I had not been able to take her home for visits while she was covered by Medicare in the nursing home, once she began on Title 19 I began, with the help of my cousin taking her

home 2 or 3 days a week. He is big and strong and was able to lift her and put her in the car. She was happy to be back in her home and reunited with her cat. And it was very, very hard at the end of the day to return to the convalescent home.

Dot Gifford had lost the ability to walk, and even standing had become difficult. The nursing home decided she would have to be prescribed a hooyer lift. This ruling carried an unfortunate caveat. My cousin and I would no longer be able to take her home in the car. It was not "safe" all of a sudden. She could only leave the nursing home facility in a wheel-chair accessible vehicle. They suggested the town transit bus, but there was no way the bus was going to go up her long, one lane, bumpy dirt driveway with no turn around space at the end.

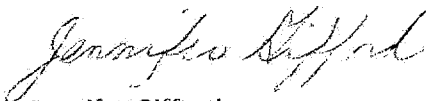
For her last six weeks at the nursing home my mother was unable to leave. Finally, on May 8<sup>th</sup>, 2014, all had fallen into place and a wheel-chair accessible Hunter's Ambulance returned her to her home and her cat. In the past 5 months she has gained almost all of the 40 lbs back. She has not had pneumonia, and has not had a UTI. Under her doctor's supervision we are gradually weaning her off all the behavior controlling medications she was put on in the nursing home with the result that she is calmer and more alert.

She is taken outside in good weather three times a day to sit in the sun. Her cat sleeps next to her during naps and at night. She especially enjoys weekly visits from her youngest great-grandson. And she can go on all the car rides she wants.

Dot Gifford deserves to spend the rest of her days in the home she has loved for so long. The idea of her having to go back to a nursing home is heart breaking. And she would never see her home again. I still have not been able to acquire a wheel-chair accessible vehicle.

I ask all of you to please do everything in your power to prevent such a tragedy.

Sincerely,



Jennifer Gifford